



Media release

17 July, 2017

Research exposes systematic barriers those with invisible disabilities face in NZ throughout their entire lives

Significant barriers throughout the lifespan of people with invisible (or hidden) disabilities have been identified in a wide-ranging review of the disability sector. It reveals alarming inequity in education services, the health system and justice system, with children and their families facing repeated challenges to receiving support and funding in schools, and lifelong discrimination due to uninformed societal attitudes.

The question being asked is why sectors such as health, education, social development and justice have failed to implement their own policies, leaving those with invisible disabilities and their families only partially receiving the services they are promised.

Invisible disabilities include specific developmental disorders, or conditions including muscle weakness, coordination and communication difficulties, cognitive delays, specific learning disabilities, emotional and behavioural problems and lack of inhibition leading to socially inappropriate behaviour.

“We are so proud to be part of the first significant NZ-only research paper for the invisible disabilities sector. This paper is a direct reflection of what it is like for young people and their families to live with an invisible disability in New Zealand. They’ve also given us some amazing feedback on how the system needs to change so they can reach their full potential”. Says Sonia Thursby CEO for YES Disability North Shore.

“Invisible disabilities is the fastest growing area of disability – we need to recognise this group as a key stakeholder in developing the services and systems that meet their unique needs. It’s time we confronted the facts - the system is not meeting their needs and it’s time to ask the question - what are we going to do about it?”

“Here at YES we are leading and supporting collaboration of providers who are committed to making the change to support the people they represent. We need New Zealand to embrace the changes across society so everyone can make the contribution they want to, regardless of impairment.”

The recommendations contained in the report are directly related to the aspirations of our young people captured in stories – so everyone can understand their reality. We hope this report ensures the generosity in sharing their realities mean positive change for future generations.”

Gap between policy and practice

The research shows that in the primary and secondary education sectors, there are wide gaps between what educators say about inclusion and what actually happens. It reveals that most educators have had very little formal training about disability, and often teachers’ interpretations vary drastically. Untrained teacher aides are

frequently left with the job of adapting the curriculum to the best of their understanding.

Both parents and teachers noted that obtaining services could be made much easier and that there is a general perception of parents and educators 'having to fight for support.'

The report reveals that families are overwhelmed, anxious and disempowered when they encounter barriers to enrolment and participation in the education system that promises that they will be catered for.

Lack of inclusion and funding

An 'alarming 13%' of children with disabilities do not attend school all day. Parents stated that inclusion is not only about funding hours and budgets, but also about teaching models. Parents' expectations of good services from Special Education services has decreased from 67% in 2011 to 60% in 2015.

Parents report frequent negative experiences of issues regarding lack of funding, lack of teacher knowledge, negative teacher or school principal attitude. 33% of families report restrictions on their child's hours of attendance, and expectations that families fund teachers' aides.

60% of these parents have the perception that their children's education is inferior, and despite the Ministry of Education policies of inclusiveness, that their children with invisible disabilities did not receive the same benefits of a free and compulsory education as their non-disabled peers had.

Parents are often referred to extra-curricular programmes instead of there being support or skills being provided within the 'inclusionary' school system.

Around 40% of parents reported a negative and bullying climate for their child, and lack of curriculum adaptation.

Increasing responsibility has been placed on schools without additional funding to enable the schools the capacity and capability to do this. The Ministry needs to recognise that significant change requires significant investment.

The impact on students and families

The consequences of these gaps in the education system are significant; young people with neuro-disabilities are over represented in stand-downs and suspensions.

The children and youth themselves report psycho-social challenges which have a negative effect on their physical health, and on their daily functioning and emotional well-being. The report reveals the dilemmas of help being delivered in demoralising and inappropriate settings, and the frustrations of not being able to obtain the level of expertise required.

It points out that the system is lacking planned decision-making between disability and education sector groups, such as service providers or stakeholder groups.

The way forward

The Invisible Disabilities Cube Collective is committed to continuing to work together directed by the voices of their stakeholder group. They need to be recognised as key partners with government departments; co-designing policy development, implementation and review. More research is needed in areas such as health, education, justice to ensure that project and programme design is meeting the true needs of the stakeholder group. Early diagnosis/intervention, increased recognition and clear pathways of support need to be made a priority for this sector to ensure we are supporting those in need ASAP.

It is increasingly recognised that visible disabilities have overshadowed invisible disabilities, not only within mainstream society but also the disability community itself.

This research uses 100% New Zealand-based information to highlight the experiences of young people with invisible disabilities, and their families, with the aim of improving their today and tomorrow. .

- Ends -

For more information please contact:

Sonia Thursby

Chief Executive of Yes Disability Resource Centre

Sonia@YesDisability.Org.Nz

0294836487

Notes to editor

1. Proportion on New Zealanders with disabilities

The 2013 census showed that 24% of New Zealanders have a disability –a sum of 1.1 million people.

- Invisible disabilities make up 18% of all people with disabilities (165,000 people.)
- In those aged 0-14 with disabilities, 59% (52,000 children) have invisible disabilities.
- In those aged 15-44 with disabilities, there are 23% (60,000 people) with invisible disabilities.

2. Current legal status

IMM (Independent Monitoring Mechanism) released a report in 2016 that concluded that disabled children are still facing barriers that prevent them from successfully engaging in education. Despite drastic policy changes to special education provision, there have been no amendments to the education Act 1989 for over two decades.

3. Current status of school offerings

The 2015 ERO report “inclusive Practices for Children with Special Needs in Schools’ concluded that 78% of schools rated themselves as inclusive, positive and having set up systems to meet educational needs. However ERO noted that there was a lack of review of the effectiveness of these systems and programmes. The limitation of this ERO report was it used a self-reporting method from schools, and ERO did not survey the parents.

4. Previous reports

The Government has commissioned a series of reports over the past decade about Inclusive Education which has produced numerous recommendations, but it has been noted that these have not been made public, and that large stocks of programmes face little review.

5. Research method

The research has shown that information gathering needs to use a wide range of data collection angles to make sure those with invisible disability aren’t being disadvantaged or misrepresented through standard data collection methods.